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Peanut allergy as a family project: social relations and transitions in adolescence

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The authors declare no conflict of interests in relation to this study.

ABSTRACT

Aims and objective: to explore and better understand the impact that peanut allergy can have on family experiences in everyday life through interviews with individual family members.

Background: Peanut allergy affects adolescents' quality of life through the need to avoid eating peanut-containing food and the risk of anaphylaxis. Adolescence is a period of increasing separation from parents and has the highest risk of food fatalities.

Design: A qualitative interview study taking a phenomenological-hermeneutic approach.

Methods: Data were generated through semi-structured individual interviews with the adolescent with peanut allergy, and both parents and a sibling. Five families were interviewed, with 20 participants in total. The theoretical foundation was the family as an interactive system, and data were analyzed with Ricoeur's theory of interpretation.

Results: The consequences of peanut allergy appeared to affect all family members and required knowledge and understanding, especially in the social network. Siblings took responsibility and had concerns for the well-being of the adolescent with allergy, while parents expressed difficulties with their child's transition to independence and their subsequent loss of control. Social relations with new family members or friends were challenged by lack of knowledge about the potential seriousness of peanut allergy.

Conclusions: Risk and uncertainty were permanent companions for the adolescents with peanut allergy and their families. It takes time to acquire the necessary understanding about peanut allergy and the risk of anaphylaxis. The adolescent's social network also needs this knowledge during the transition to independent living.

Relevance to clinical practice: In the management of peanut allergy in adolescence, it is important to consider not only the smaller biological family unit (mothers, fathers, and siblings) but to also take a wider perspective to include others such as stepfamily and friends.

Keywords: adolescents, family, food allergy, siblings, everyday life, family nursing, anaphylaxis, qualitative methods, parents

What does this paper contribute to the wider global clinical community?

- This study provides an insight into the impact of peanut allergy on the everyday life of adolescents patients and their families
- Nurses and healthcare professionals need to see the family in a wider perspective to involve siblings and parents of adolescents with peanut allergy as well as new family members

- Health professionals can help the adolescent with peanut allergy to make the transition to independent living and should recognize that the adolescent's social network is important in managing peanut allergy

INTRODUCTION

Peanut allergy is known to have impact on adolescents' quality of life (Flokstra-de Blok *et al.* 2008, van der Velde *et al.* 2011) and is rarely outgrown, in contrast to other food allergies such as egg and milk (Anagnostou & Clark 2014). It is unusual in that the individual has a chronic condition but remains well, though with the potential to become acutely and severely ill due to anaphylaxis (Cummings *et al.* 2010). Stress and anxiety are described in families living with the risk of anaphylaxis (Akeson *et al.* 2007, Gallagher *et al.* 2012, MacKenzie *et al.* 2010).

Management of peanut allergy is limited to avoidance of the implicated food through elimination diets (Cummings *et al.* 2010, Knibb *et al.* 2012). Avoiding peanut can be difficult as it is used in many different foods, and labelling can be inadequate or misinterpreted by the adolescents and their families. There is also a risk of contamination with peanut protein during the manufacturing process of other foods or when making dishes at home or in restaurants. In emergencies, the treatment of peanut allergy consists of using an epinephrine auto-injector (EAI). This should be carried at all times, but is not always the case (Gallagher *et al.* 2011, 2012, Marrs & Lack 2013, Saleh-Langenberg *et al.* 2015, Sampson *et al.* 2006). For safety reasons it is important to identify situations with high risk of anaphylaxis and to learn how to react appropriately.

Adolescence is a period of increasing independence and greater separation from parents and is the age group with the highest risk of food fatalities through anaphylaxis (Bock *et al.* 2007, Monks *et al.* 2010). Responsibility for managing food allergy is transferred from parents to adolescents, who increasingly eat out with friends rather than with the family and thus need to pass on allergy knowledge acquired in the family to their social network. Separation from parents can involve risky situations because adolescents often feel a need to conform and can choose to ignore the allergy (Akeson *et al.* 2007, Gallagher *et al.* 2012, Greenhawt *et al.* 2009).

In the last decade, there has been a growing interest in the development of questionnaires to measure the impact of food allergy (DunnGalvin *et al.* 2015). Previous qualitative and quantitative research on food allergy in families has typically involved mothers as caregivers (Akeson *et al.* 2007, Knibb *et al.* 2016, Stjerna *et al.* 2014, van der Velde *et al.* 2013, Warren *et al.* 2016). Only two studies were found involving fathers – one in which mothers reported higher impact on quality of life and greater anxiety and stress than fathers (King *et al.* 2009), and another in which mothers reported reduced quality of life but greater empowerment compared to fathers (Warren *et al.* 2015).

We thus know little about how peanut allergy affects the everyday life of other members of the family, such as fathers and siblings. Events such as disease or illness in one family member can have an impact on all family members, hence the focus on the family as a system with interacting components i.e. a system that is constantly moving, changing and non-static (Wright & Leahey 2013).

The aim of the current study was to explore and better understand the impact that allergy can have on everyday life in families with an adolescent/young adult with peanut allergy.

METHODS

Interviews and participants

This qualitative study used a phenomenological-hermeneutical approach inspired by Paul Ricoeur's theory of narrative and interpretation (Lindseth & Norberg 2004). Individual semi-structured interviews were conducted with adolescents and their families using a thematic interview guide (Kvale 1996). Main topics were constructed beforehand that were expected to elicit the family members' perspectives on living with peanut allergy (Table 1). These topics were inspired by the literature and from clinical and research experiences in the allergy center.

Purposeful sampling (Palinkas *et al.* 2015) was used to ensure a wide range of family perspectives. Patients aged 15-16 years with a diagnosed peanut allergy (as the primary allergy) and at least one sibling above 12 years of age were recruited from an allergy center at a Danish university hospital. Patients were excluded if they had a psychiatric disorder, intellectual disability, other major diseases, or poor understanding of the Danish language.

Approximately 14 days before the interviews, a written information letter was sent to the participants. The letter included two preparatory questions asking participants to reflect on: *"What does it mean for your everyday life that you have a peanut allergy? Is there a single, or several, everyday situations that have made a special impression on you that you would like to tell me about?"* Interviews were conducted with the adolescent with peanut allergy, the mother, father, and one sibling and lasted 45-60 minutes. All interviews were conducted in each family's home with one family member at a time.

Data analysis

Interviews were recorded and transcribed verbatim, and all participants were anonymized. Data were entered into the software program NVivo.

Data were analyzed inspired by Ricoeur's theory of interpretation in three stages: 1) naive reading, where the transcriptions were read and re-read to develop an overall understanding of the text content, 2) structural analysis (Fig. 1), a dialectical process between understanding and explanation, where central units of meaning (*what is said*) and units of significance (*what is the text talking about*) were identified, leading to key themes about living with peanut allergy, 3) critical interpretation and discussion of the analyzed themes in relation to relevant theory, current research, and implications for clinical practice (Lindseth & Norberg 2004). We validated the findings by discussing a selection of the interview transcriptions and the identified themes first with three nurse specialists in skin/allergy, and then amongst the interdisciplinary research team.

The analytical approach was based on the theory of systemic family nursing (Wright & Leahey 2013). In the family system, there are individual systems such as the adolescent with peanut allergy, the sibling, the mother, and the father, and each of these individual systems is both a part of themselves and a part of the whole family. At the same time, the family unit exists in a larger suprasystem of all the social relations and activities occurring outside the family. This suprasystem is composed of

many subsystems such as friends, school, sport activities, trips, restaurants etc. From this point of view, the family is seen as a non-static system of interacting components – a system that is constantly moving and changing (Wright & Leahey 2013).

Ethical considerations

Written informed consent was obtained from all participants (and from the parents for participants aged under 18 years). We provided participants with oral and written information about the study. Anonymity was ensured, and recordings and transcribed material were stored according to the Danish data protection laws. The study was registered at the Danish Data Protection Agency (ID number: 2008-58-0035). The project did not require approval from the regional committee on health research ethics. The participant quotes cited in this manuscript have been translated from Danish and are identified according to Table 2, except for two quotes that have been anonymized by calling "X".

RESULTS

A total of five families were included (Table 2), including five adolescents with peanut allergy (two boys and three girls aged 15-16 years), five siblings (one boy and four girls aged 14 to 20 years), five mothers and five fathers (including one stepfather). Four of the five siblings were older than the adolescent with peanut allergy. In three families, the parents had divorced, and both parents had a new partner. The adolescents had had peanut allergy for as long as they could remember, and all had experienced severe allergic reactions. They all had an epinephrine auto-injector.

Three main themes emerged from the structural analysis:

- 1) The nuclear family - safety and understanding
 - Peanut allergy, a learning process
 - Perspectives of the siblings
- 2) When the nuclear family is challenged
 - Divorce
 - Risk management
- 3) The importance of having a social life.
 - School, friends, and new relationships
 - To be in control

The nuclear family – safety and understanding

During the interviews, it became apparent that routines in everyday life were considered important for all members of the family to feel safe and in control. Having a child with peanut allergy affected all members of the family, and they all learned about peanut allergy from several sources throughout the years. They had been to the allergy center for food challenges and check-ups at least once a year. Family members explained that they had to be alert in all situations where food was involved. During the interviews, it became clear that safety and knowledge about the consequences of the illness were essential for all.

Peanut allergy, a learning process

The home was described as a safe place, especially in the families where the parents lived together. They talked about the importance of helping and learning to live with peanut allergy in terms of family as a whole. A father expressed:

"I think that for the project to succeed, our family project to prepare him for life, it is important we provide a common understanding to the other siblings" (F2 fam 2)

Each family had their own routines that made them feel safe and in control. Some families removed peanuts and all food that could contain peanuts from the home, and siblings only had peanuts in their food if their sister/brother was not at home or if they were visiting friends. Other families found it important not to convert the whole family to a peanut-free diet, but to normalize others eating peanuts. This was also a way of training the adolescent in handling the risk in everyday life and to avoid over protecting the child. One mother said:

"Because if you remove all attention from it at home, then it's easy to forget about it when you are out" (M4 fam 4)

Siblings, fathers, and the adolescents with peanut allergy described the mother as a resource and the most knowledgeable person concerning peanut allergy. All the fathers considered the mothers to be the most anxious about food fatalities; this was confirmed by the mothers. Siblings pointed out that their mother was important for security:

"But if my mum comes along, then I think the situation is safer. I think, I don't know, but I think she [my sister] has faith in my mum to make sure there are no peanuts in anything" (S4 fam 4)

The parents felt it had been a long learning process to accept the everyday life with the risks and consequences of living with peanut allergy. They tried to focus on possibilities instead of limitations and to use the difficulties as a chance to learn and develop. Parents explained that their children with peanut allergy developed a stronger personality and faith in themselves, and thus the whole family had received a gift of being able to accept weakness and challenges in life. One of the boys with peanut allergy said:

"I would just say: Look at what you can do instead of what you cannot. My parents usually say that if you see life as a supermarket, there are a few shelves you cannot take from, but there are a whole lot of other shelves you can take from, so look at them instead" (A2 fam 2)

The parents and the adolescents with peanut allergy talked about the allergy center as the place where they all had received their knowledge and understanding about peanut allergy and how to handle it. The family members said that the center provided the specialist care and treatment they had been missing earlier. They liked the health professionals' approach and described it as competent, with humor, warmth and a professional approach. The adolescents were glad not to be scolded by the staff. The siblings added another perspective, as they had not experienced the allergy center; instead they acknowledged their parents' efforts and energy in supporting their brother/sister:

"They [our parents] have meant all the difference. Although the staff at the hospital have told him what he can and cannot eat, in reality, it's still Mum and Dad who have taught him what he can eat and what he cannot eat" (S3 fam 3)

Perspectives of the siblings

During interviews with siblings, it became clear that especially the older siblings were very protective and took responsibility for their sister/brother with peanut allergy. The older siblings reported that their younger siblings with peanut allergy were more reflective and more mature, but also more in control and perfectionist than themselves.

The siblings had acquired knowledge and experience through several years of living with peanut allergy through their sister/brother. It had not been possible for the sibling to go with their sister/brother to the allergy center because of school. However, all siblings knew that their sister/brother was living with high risks and anxiety. A sister told about an experience when her allergic sister thought she had eaten a peanut:

"I think she could feel it, I don't know if it was a nut or a peanut or something, but she became really scared that she had eaten this peanut. And for me, I think it was not so much that something might happen, but more seeing how panicky she became. I think she brushed her teeth for the next half-hour and sort of ran off because she got really scared. I think that's what really surprised me the most, how scared she became" (S4 fam 4)

All siblings had seen their sister/brother have a severe allergic reaction caused by traces of peanuts in food. One sibling told about an episode where her sister had eaten a cake she couldn't tolerate. The sibling ran up to her sister's friend's house with antihistamine and adrenaline, waiting together with her sister for an ambulance, because their parents were at work. The sisters to the adolescents with allergy mentioned their own fear of losing their sister/brother and – except for one mother – were the only ones that mentioned "death" related to the risk and consequences of living with peanut allergy. The anxiety and worries about what could happen to their sister/brother in emergencies had great influence on them. All interviews with siblings began with stories about calling ambulances and their sister/brother going to hospital, and the fear connected to the risk of losing them. A younger sister explained:

"For the most it is OK, [but] when he gets collected by ambulance, then you can get a bit scared that there had to be a whole ambulance for him to get through this." (S2 fam 2).

The sibling's fear of losing a sister/brother was also recognized by some of the parents. A mother told about when her child with peanut allergy was about to try some food she really wanted to taste and that the mother had allowed her to taste a little bit. The mother described her other child going totally berserk, screaming whether the mother wanted her sister to die.

When siblings talked about their family, they didn't think that their parents were more caring or overprotective to their sister/brother with peanut allergy than to themselves. The parents said that they tried to handle all their children in the same way; however, they also said that they were more nervous if the child with peanut allergy was to go on a school trip, a journey or a festival. A father

said he was closer to his son with peanut allergy because of all the times he had been ill and the visits to the hospital. He said:

"Sometimes I can't help wondering whether I have, well I know I have, spent more time on [the son with allergy] than his brother. What effect that has had on him, I don't know. But I have focused more on [the son with allergy], that's for sure, because of his illness. So sometimes his brother has missed out." (F3 fam 3)

When the nuclear family is challenged

In the families where the parents were divorced, the daily routines and ways of controlling situations were challenged and changed. Routines which the nuclear family had built up during years of experience were broken down. Risk situations challenged the families even though they had knowledge of key management strategies such as allergen avoidance and carrying the auto-injector.

Divorce

The new family member's lack of knowledge about peanut allergy was expressed as being a severe challenge and a risk to the allergic adolescent. One boy whispered that his stepmother did not understand how serious his peanut allergy was. He said that she used the same knife for food he could and could not tolerate, and thus contaminated his food. He said:

"I think to myself and hope my dad will say [to his girlfriend] 'Hey listen, please take the other knife'. He should do it, because I don't like to say it. It's not me who should do it, he is the grown-up" (AX fam X)

The stepmother's lack of knowledge had created a gap between the son and the father, who had previously been close. Helping to prepare the food was something that several of the teenagers with peanut allergy were happy to do, and some of them said that making food was like a "passion". This could also be a way of controlling the food preparation. However, it could become complicated if stepparents did not have the same knowledge. Parents and adolescents explained that new stepparents had difficulties in understanding the risks and serious aspects of suffering from peanut allergy. One father said:

"She sometimes says 'It can't be right we always have to show consideration' - as long as we make sure there is something else for him and not just rye bread" (FX fam X)

The examples reflected the challenges the nuclear family faced when parents broke up and found new partners. However, we also heard about biological fathers being on the wrong track, including putting plasters on his daughter's skin, not allowing allergy medicine, and eating in a Chinese restaurant despite his daughter being afraid of food contamination and refusing to eat anything.

It could be difficult for newcomers to understand the seriousness of peanut allergy when they had never experienced an allergic reaction, and especially as the adolescent with allergy appeared to be completely well. A father said that he was annoyed with himself for not taking pictures when his child had an allergic reaction then he could have shown other people how serious it could be. A mother said in the context of a food challenge;

"I think the staff should encourage both parents to observe [a food challenge]. It shocks you when you see your child completely out of it. If you didn't know before how serious it was, then you certainly know when you have seen it." (M4 fam 4)

Risk management

The adolescents with peanut allergy explained that the trigger for previous anaphylactic shock had been a piece of cake, crispbread, or a burger. All participants thought it was very difficult to manage the risk of an allergic reaction. The families mentioned a hope for a vaccine against peanut allergy, or that the adolescents could at least tolerate food containing only “trace of” peanuts. Inadequate labeling and labels stating “may contain” or “traces of” complicated management, as a father said:

“It would be a very big step forward if she could get over some of it and could tolerate traces of peanut [in food]. Which she might or might not be able to tolerate now. But the ‘traces’ – they can be small or large.” (F1 fam 1)

The recommended treatment of peanut allergy in emergencies is the epinephrine auto-injector (EAI). The families told about emergency situations with severe allergic reactions but nobody mentioned the EAI until asked about it. Even though having the EAI was clearly a security for all family members, one sibling said:

“Well, I would feel unsafe without it. But, well not complete safety, because I know that she is really bad to remember it.” (S1 fam 1)

The adolescents with peanut allergy and their siblings were afraid of using the EAI. The needle was scary, and they were also afraid of the consequences of using the EAI, as they had been instructed to call the emergency number 112 afterwards. The adolescents with peanut allergy said that the EAI was always in their schoolbag, but they did not use schoolbags in leisure time. During leisure time, “I remember it as often as I can” (A1 fam 1) or else the EAI was always with them – “except if I forget it. Now and then you forget it, otherwise I always have it in my schoolbag or somewhere” (A3 fam 3) or “When my mum says that I should take it with me” (A2 fam 2). They all gave several reasons for not taking their EAI with them, for example, the proximity to home of the place they were visiting, the absence of airway symptoms, that they had not needed the EAI before. Parents also mentioned some of these reasons. Parents and adolescents preferred to use antihistamines rather than the EAI, because they were more familiar, were easier, and did not require a 112 call. Several of the families had called 112, but none of them had used the EAI before calling.

The importance of having a social life

All parents expressed the importance of their children having a social life, and they wanted them to live a “normal” life despite the peanut allergy.

School, friends, and new relationships

The adolescents said they felt secure when they were together with friends who knew them well, but at the same time they could end up feeling sad, embarrassed, or a burden if they couldn’t eat the food their friends’ parents had spent a long time preparing. Making new friends was described by all the adolescents as difficult, because new friends did not know about their allergy and what they were able to eat. The adolescents with peanut allergy had to check everything before eating, and they were afraid of being a nuisance. One boy had to move to a new school because one of his

parents was moving to another city. He described vulnerability and was unhappy, as he wanted to stay with his old friends:

"I find it hard visiting new friends when starting in a new school class, because you have to think about your food allergy. Does it contain this or does it contain that? And when you buy something new in [the supermarket], you also have to check if you can eat it" (A3 fam 3)

Eating in restaurants was described as an important part of their social life but also a challenge. The adolescents with food allergy could not go to a random restaurant and eat. One of the girls told about a school trip where her classmates chose a restaurant where she couldn't eat. She felt that the food allergy limited her relationships:

"Not being able to eat what everyone else eats can be a bit annoying and particularly having to eat something separately, after everyone else has eaten. I feel it ruins the social part of it, because I can't really participate in the same way as everyone else" (A5 fam 5)

All the adolescents had experienced a lack of understanding for their peanut allergy. Three of the five adolescents had experienced bullying from their peers at school such as giving them a peanut to eat, throwing peanut at them, or threatening to put a peanut in their food. The adolescents with peanut allergy had tried to explain to their classmates that they could die of it, but only their closest friends believed them. Another form of bullying was school treats if someone had a birthday. Sometimes there was nothing they could tolerate due to their allergy, at other times they were given other treats and some of the peers thought this was cheating. One boy said:

"It can make me sad when I am given something different to the others, especially when I really would like to eat what they get, even if it's not as nice as what I get. I also get sad when people say it's cheating that I get something different. I don't think it's fair they say that and I tell them "you try and live with a food allergy". It's not much fun when people think it's cheating, because I didn't choose to get a big bag of sweets instead of a piece of cake. Sometimes I think people are rude" (A3 fam3)

All the adolescents with peanut allergy expressed happiness when schoolmates brought special treats they could tolerate – they described these treats in detail, what it was and what it looked like. It meant a lot to them not to be different. Feeling normal could also be by striking up friendships with schoolmates who had other illnesses. Two of the girls said that they had a best friend with diabetes. One of them said:

"I have a friend with diabetes. She can't eat everything either, so we just sit together without eating and just talk to each other" (A1 fam 1)

To be in control

When the adolescent leaves the home to be together with friends, the rest of the family can experience uncertainty, as expressed by a sibling:

"...often when he is elsewhere. At home, I know that Mum has checked that there is nothing [in the food]." (S3 fam 3)

Parents did not want to limit their child with food allergy in doing things they wanted to do but were always on alert if something happened – they were “standing just behind the door” and were 100% available by phone, which they explained was different than for their other children. The parents knew there was a risk of anaphylaxis and that it could be fatal if their child did not get the correct treatment. Planning of food was very important to them when the adolescent left home alone in different situations. Some of the parents prepared packed lunches for their child, while others contacted the place the child was going to visit. One father told about his son visiting a boarding school, where – despite the planning and talking to the boarding school – his son got a severe allergic reaction. Afterwards, the father blamed himself for relaxing:

“I shouldn’t have been relaxing with a couple of glasses of red wine with my girlfriend. I had been comfortable leaving him with [the school], thinking they knew what to do, and yet it went wrong. It is always there – I know there is a risk and that you constantly have to try your best to avoid something happening.” (F3 fam 3)

All parents agreed that their biggest fear was their child getting an allergic reaction when they were not there to help them. The physical distance to their child thus had great impact on their everyday life. The fear was worst when their child was travelling to another country on a school tour or with the sports club. A father told about a Skype conversation from the US with his daughter, who had called him because she had eaten some food that she could not tolerate and she was feeling very ill:

“It was a rather uncomfortable to think she was over there feeling unwell. But it helped that we could talk together about it and that we could feel that she wasn’t scared.” (F5 fam 5)

Some of the adolescents with peanut allergy found it irritating that their parents worried and wanted to control their lives. The adolescents tried to tell their parents to take it easy and to trust their ability to take care of themselves and be responsible. Some of them described how they got more observation from their parents than their peers at the same age. One girl said:

“Sometimes it’s a bit annoying to have to say to my friends, “I just have to text my parents”. They also often call me to ask how my day went. So sometimes I feel my parents are a little irritating, but they only do it to look after me, so that can only be good.” (A5 fam 5)

Alcohol is a part of most Danish teenagers’ lives, and all parents said they were scared about their child’s alcohol debut. This was also the case for the siblings, but the adolescents with peanut allergy hardly mentioned alcohol. Parents and siblings explained their fear that alcohol would make their child/sibling less alert and less in control. All parents thought an environment with drunken people and nobody to take responsibility was very worrying and disturbing. Another serious worry they mentioned was the risk of kissing a girl/boy who had eaten peanuts, as this alone could cause a severe allergic reaction.

DISCUSSION

This qualitative study has provided an in-depth picture of the concerns and everyday life of adolescents with peanut allergy. Based on the notion that events such as disease or illness in one family member can have an impact on other family members, we focused on the experiences of the whole family including siblings. The findings show that coping with peanut allergy requires

knowledge and understanding, which was specifically expressed in terms of social relations. The adolescents with peanut allergy felt safe in known situations with family and friends, but felt challenged in relationships and situations where people did not have knowledge about peanut allergy. Learning how to cope with peanut allergy was a long process, and the adolescents with peanut allergy and their families had learned to manage it through repeated exposure to risk situations, including the possibility of anaphylactic reaction.

When offering support to the adolescent with peanut allergy and their family, nurses and health professionals need to understand that the family is part of a larger system (Wright & Leahey 2013). They should recognize that the family is a moving and changing entity. Although the nuclear family is still most common, divorce and remarriage are increasing, and the family needs to be seen in a wider perspective that includes the consequences for peanut allergy of new stepparents and stepsiblings. Adolescence involves increasing independence from parents, and our results highlight the importance of a wider focus including the suprasystem of subsystems such as friends, school, and other social occasions. Food allergy can have a negative psychosocial impact on young people and their families (Cummings *et al.* 2010, Mandell *et al.* 2002), and balancing safety and quality of life can be a challenge for adolescents (DunnGalvin *et al.* 2009, Gallagher *et al.* 2011, MacKenzie *et al.* 2010, Monks *et al.* 2010).

The siblings interviewed in our study described their sister/brother with peanut allergy as being more reflective, mature, perfectionist, and in control than themselves. This could be related to the peanut allergy, which impacts directly on children's normal trajectory of psychological development (DunnGalvin *et al.* 2009). The siblings appeared to be very protective and took responsibility for their sister/brother. They often worried about what could happen in emergencies due to peanut allergy and were afraid that their sibling with peanut allergy would eat food contaminated with peanut and could die from it. However, girls with peanut allergy reported significantly poorer quality of life and more separation anxiety and anxiety for physical injury than their healthy sisters (King *et al.* 2009). Boys with peanut allergy had similar anxiety ratings to their brothers but reported lower quality of life (King *et al.* 2009).

Although the fathers interviewed in our study worried about their children with peanut allergy and took responsibility for handling it, the main responsibility seemed to be taken by the mothers. The regular family rhythms are changed when the biological mother and father stop living together and new family members appear. The 'new' family has to start again in building up knowledge and experience, and this can cause friction with a new partner or between stepparents and stepchildren. The mothers tended to have a more prominent role than the fathers in managing the food allergy, and this can be a problem if the adolescent then starts living with their father part of the time. The previous finding that mothers reported greater empowerment but reduced quality of life compared with fathers (Warren *et al.* 2015) could be because mothers are typically the primary caretakers in the family (Howe *et al.* 2014, van der Velde *et al.* 2009). Interestingly, Warren *et al.* found that although both (married) parents reported high levels of empowerment related to their child's food allergy, they also reported reduced quality of life due to food allergy (Warren *et al.* 2015). In another study, mothers reported higher impact on quality of life and more anxiety and stress than fathers did (King *et al.* 2009).

Those we interviewed expressed a strong wish for a vaccination against peanut allergy or a hope that in time the adolescent would be able to tolerate food labelled as possibly having “a trace of peanuts”, as this could help the whole family. They explained it was difficult to avoid peanuts and “trace of peanuts” in everyday life as peanut is used in many food items, and food is important for social interaction. The parents were highly knowledgeable about their child’s allergy and were aware of the risks and how to take care in their own home. Parents were anxious, however, about handing over the main responsibility for avoidance and emergency treatment to their children, as reported elsewhere (Akeson *et al.* 2007). The parental burden can be significantly increased due to allergen exposure outside of the home or away from the parents, for example with social activities involving foods, restaurants visits and vacations (Warren *et al.* 2015). In line with this, most cases of food-induced anaphylaxis occur outside the home (Bock *et al.* 2007, Pumphrey & Gowland 2007).

In our interviews, the adolescents with peanut allergy described an allergic reaction as being unpleasant, and they mentioned the frustration of possibly missing out on social events and other aspects of life rather than the risk of death. Checking food labels, the risks associated with eating out, and deciding whether or not to carry the EAI are aspects that have been identified as being socially difficult for adolescents (Akeson *et al.* 2007). Risk-taking behavior among adolescents is well known in the management of food allergy (MacKenzie *et al.* 2010, Monks *et al.* 2010), and the adolescents in our study did not always carry their EAI with them, especially if they were going only a short distance from home or had not previously had to use it. Similarly, a UK study showed that adolescents and their parents did not always use the EAI even if the reaction was recognized as anaphylactic and the EAI was easily available (Gallagher *et al.* 2011). Although their management strategies may be inconsistent with best clinical practice, adolescents tend to view them as “good enough” (Gallagher *et al.* 2012). Food allergy has a strong psychosocial impact, and it may be the risk of food reactions and the measures taken to avoid them that reduce quality of life, rather than the severity of the clinical reaction (Marklund *et al.* 2006).

The parents in our study found it important for their child with food allergy to have as normal a social life outside the home as possible, but this also meant less control over their child’s behavior. This transition in the individual system from childhood dependence to adult independence is a condition of adolescence. It was also challenging for the adolescents we interviewed to experience new social situations and to form new relationships due to the lack of awareness about allergy among their peers. They faced challenges such as school bullying even amongst people they knew quite well. A lack of understanding among classmates about the potential seriousness of food allergy has also been reported in other studies (Dean *et al.* 2016, Monks *et al.* 2010, Sampson *et al.* 2006). The adolescents in our study had experienced school trip to restaurants where they could not tolerate the food as, for example, peanuts are common ingredients of Asian, Chinese and Mexican cookery. The general public perception of food allergy impacts on the life of adolescents (Lyons & Forde 2004), and for the adolescents in our study it meant a lot to them not to be different.

Due to adoption or remarriage, the ‘family’ can be more than the classical, biological nuclear family, and it is the individual who determines who their family is. Rempel *et al.* suggested the use of a genogram, a graphic description of the family structure, and an ecomap, a graphic description of the social relationships at both the personal and the family level (Rempel *et al.* 2007). Whereas the genogram is more a graph of generations in the family and reflects family history, the ecomap is a tool to develop an overview of family relationship and the forces within the family.

Strengths and limitations of the study

The main strength of the current study is the in-depth interviewing that produced rich and nuanced accounts of how adolescents and their families (siblings, mother, father) manage peanut allergy. We included only patients and families who had had peanut allergy for several years, however, and the findings may have been different if we had included adolescents with newly diagnosed allergy. Only one of the siblings was a boy, and all but one of the siblings were older than the adolescent with peanut allergy, and this may also have affected the findings. The most obvious limitation of the study, as in many qualitative studies, is the relatively few participants and the potential restrictions this places on the generalizability of the results. Data saturation was reached, however, and the insights from our in-depth approach are likely to be transferable to adolescents with peanut allergy living in other parts of Denmark and other countries.

CONCLUSION

The family of an adolescent with peanut allergy has gone through a long learning process, where each family member has had to acquire the knowledge and understanding necessary for managing potentially risky situations. When parents divorce and remarry, the family's comfort zone is challenged, and new family members must learn about food allergy and its management. Adolescents are in a transition stage where they are less often at home, experience new social situations and form new relationships. The resulting responsibility, the need to transfer family knowledge to new friends and contexts, and the need to be constantly on guard create insecurity for the adolescent with peanut allergy as well as for their siblings and parents.

RELEVANCE TO CLINICAL PRACTICE

In a healthcare system that aims for a patient-centered approach, eliciting the views and experiences of adolescents with peanut allergy and their families can help to improve the management of peanut allergy. It is important to consider not only the smaller biological family unit (mothers, fathers, and siblings) but to also take a wider perspective to include others such as stepparents and stepsiblings. The family with peanut allergy is especially vulnerable in divorce and remarriage, as mothers have often been the primary carers, and suddenly the adolescent may have two homes with new members who may have little knowledge of the risks associated with a food allergy.

A change in the situation of one family member is likely to affect all family members. Siblings should thus be involved in the management of food allergy so that they are not alone with their anxiety. Their concerns could be discussed, for example, in a consultation that has a specific focus on the family.

Relationships within the family are important for food allergy, but so is the network of friends who also have to learn to handle peanut allergy as the adolescent becomes increasingly independent of the family. Health professionals must be prepared to discuss the adolescent's behavior strategies in a concise but balanced way to help the adolescent cope when making the transition to independent living.

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Conflicts of interest

The authors declare no conflict of interests in relation to this study.

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Table 1. Main themes of the interview guide for families with peanut allergy

| Main themes in interview topic guides with the focal point peanut allergy in everyday life |
|---|
| Starting point: any special situation(s) that had made an impression on them in relation to peanut allergy? |
| Experiences of having peanut allergy in the family |
| Family: relationships with mother, father, siblings |
| Friends and social relationships |
| The epinephrine auto-injector (EAI) |
| Support: who has supported or meant something to you in relation to peanut allergy? |
| Thoughts about the future |

Table 2. Characteristics of participants in the five families interviewed

| Participant type | Participant number | Sex/age | Allergy |
|------------------|--------------------|---------|-------------|
| Adolescent | A1 | F 15 | Pe |
| | A2 | M 16 | Pe, Egg, Ha |
| | A3 | M 15 | Pe, Egg, Ha |
| | A4 | F 15 | Pe |
| | A5 | F 16 | Pe, Ha |
| Siblings | S1 | F 18 | |
| | S2 | F 14 | |
| | S3 | M 17 | |
| | S4 | F 17 | |
| | S5 | F 20 | |
| Mother | M1 | | |
| | M2 | | |
| | M3 | | |
| | M4 | | |
| | M5 | | |
| Father | F1 | | |
| | F2 | | |
| | F3 | | |
| Stepfather | F4 | | |
| | F5 | | |

F: female, M: male, Pe: peanut, Ha: hazelnut

Figure 1. Illustration of structural analysis

